

**'Back to Life'—Using knowledge exchange processes to enhance lifestyle interventions for liver transplant recipients: A qualitative study**

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# 1 “Back to Life” - Using knowledge exchange processes to enhance lifestyle 2 interventions for liver transplant recipients: a qualitative study.

## 3 4 **Abstract**

5 Interventions to prevent excessive weight gain after liver transplant are needed. **Aim:** The  
6 purpose of this study was to enhance a specialist post-transplant wellbeing program  
7 through knowledge exchange with end-users. **Methods:** The study used an interactive  
8 process of knowledge exchange between researchers, clinicians and health system users.  
9 Data were collected as focus groups or telephone interviews and underwent applied  
10 thematic analysis. **Results:** There were 28 participants (age 24-68yrs; 64% male). The  
11 results identified experiences that may influence decisions around health behaviours  
12 during the course of transplant recovery. Three over-arching themes were identified that  
13 impact on liver transplant recipients post-transplant health behaviours. These include 1)  
14 *Finding a coping mechanism* which highlighted the need to acknowledge the significant  
15 emotional burden of transplant prior to addressing long term physical wellness; 2) *Back*  
16 *to Life* encompassing the desire to return to employment and prioritise family, while co-  
17 ordinating the burden of ongoing medical monitoring and self-management; 3) *Tailored,*  
18 *Personalised Care* with a preference for health care delivery by transplant specialists via  
19 a range of flexible eHealth modalities. **Conclusion:** This person-centred process of  
20 knowledge exchange incorporated experiences of recipients into service design and  
21 identified life priorities most likely to influence health behaviours post-transplant. Patient  
22 co-creation of services has the potential to improve the integration of knowledge into  
23 health systems and future directions will require evaluation of effectiveness and  
24 sustainability of patient centred multidisciplinary service development.

**Key Words:** health service design, patient engagement, focus groups, obesity, liver disease, quality of life

## Introduction

Rapid weight gain after liver transplant is a world-wide phenomenon with 16-46% of liver transplant recipients (LTR) becoming obese in the first year after transplant.<sup>(1-5) (6-</sup>

<sup>8)</sup> There is a higher prevalence of metabolic syndrome in LTRs compared with the general adult population and this appears to predispose to increasing cardiovascular disease risk, graft rejection, infection and other complications.<sup>(9)</sup>

Adjusting to a liver transplant is a complex process which incorporates both physical and mental components of recovery. Liver transplant recipients endure significant physical and psychological stress awaiting surgery<sup>(10)</sup> and group-based psychoeducational strategies appear effective at improving coping strategies and social support pre-transplant<sup>(11)</sup>. There is however a paucity of data addressing how best to deliver diet and exercise prescription for post-transplant recovery and how lifestyle interventions may prevent obesity and cardiometabolic complications post-liver transplant. The development of targeted lifestyle interventions to prevent excessive weight gain and manage cardiovascular risk requires a process of knowledge exchange between service providers and patients, in order to meet the unique needs and life priorities of this cohort.

The purpose of this study is to use a process of knowledge exchange to involve knowledge users in research and explore the everyday experience of LTRs to co-create a specialist health and wellbeing program aimed at reducing cardio-metabolic risk factors post-transplant. This study aims to engage with LTRs to define life needs and priorities, and

capture the emergence of factors that influence health behaviours across the spectrum of pre- and post-liver transplant health services.

## Methods

A stakeholder group of five liver transplant specialists, including physicians, nutrition and exercise experts from a single Australian transplant centre (40-55 transplants per year) developed a framework of key factors (enablers and barriers) that could impact on the long-term health of LTR, which informed the development of this study. In preparation for a process of knowledge exchange i.e. imparting meaningful knowledge between knowledge users (LTR) and producers (investigators and health practitioners), this framework drew from components of implementation science, such as level of evidence (determined by literature review), context of health service delivery system (determined by extensive clinical experience working within the system) and unique needs of LTR (determined by both published evidence and clinical experience).<sup>(12-14)</sup> This framework was further refined with clinical consultation and reference to individual, institutional and systemic factors that impact on health behaviours including patient perceptions of weight gain and 'healthy lifestyle' post-transplant, life priorities, timing of service delivery and acceptance and feasibility of technology-assisted service models (see supplementary material) . The framework then informed the development of semi-structured interview questions designed to promote knowledge exchange and capture LTR lived experience of transplant and perceptions of health priorities in relation to long-term wellbeing (Supplementary material Table A). Data saturation determined when to cease recruitment and was defined as no new information being offered either through the knowledge exchange or prioritisation processes.

Interviews were conducted with LTRs through either focus groups or telephone interviews. Participants were offered opportunities to share experience and knowledge

during early (within 6 months of transplant) and longer term (>6 months post-transplant) health service follow-up. Participants were asked to prioritize factors that they considered most influenced their health behaviours post-transplant.

The study was approved by the [blinded for peer review]. All participants provided written informed consent (received by post for those undertaking telephone interviews).

The study population included adults who had received a liver transplant and had ongoing medical review as an outpatient of the service. Transplant registry lists were screened for eligibility with inclusion criteria of  $\geq 18$  years of age, received a liver transplant  $\geq 12$  months ago, and English-speaking. Participants were opportunistically sampled to identify those already scheduled for outpatient visits during the recruitment period (January – June 2015), and purposively recruited to achieve broad demographic diversity including gender and geographical location. Eligible patients were not previously known to the investigators (although were known to the transplant clinic) and contacted via telephone, had the purpose of the study described and invited to participate in the study. Those who agreed to participate were scheduled for a face-to-face focus group (1-1.5 hours) or a telephone interview (30 minutes) based on their preference.

Four focus groups (total participants  $n=17$ ) were conducted by investigators DC (APD, female, research student) and IH (PhD, research fellow, female, experienced researcher) over the study period and consisted of seven prepared questions. There were no non-participants present. Each group also developed a list of life priorities to identify the most important influencing factors in their lives at three different time-points across the transplant continuum: pre-transplant; early post-transplant (within 6 months); and  $\geq 12$  months post-transplant. Participants were encouraged as a group to name life priorities at

each of the three time points until no new priorities were identified. These were listed in order of mention on a whiteboard for all to see. When all participants had considered the group list, they were each asked to anonymously write down the top five most relevant issues to them personally for each time point, in order of priority for them as an individual. This could include priorities that had not been discussed by the group. The participant's priority list was given to the investigator without sharing with the group.

All discussions were audio recorded and transcribed for data analysis. Certificates of appreciation were presented to participants on completion.

The option of a telephone interview was offered to participants who could not attend face-to-face due to geographical distance or personal commitments and was chosen by 11 participants. The choice to use both focus groups and interviews in this way was to ensure broad participant diversity, and to offer opportunities to voice issues that the participants may have been uncomfortable to discuss in a group setting. Due to lack of group dynamics, the priority listing exercise was modified for individualised interviews.

**Data Analysis:** Data were reported according to the COnsolidated criteria for REporting Qualitative research(15). Interviews and focus groups continued until saturation of themes was reached. Audio recorded data from focus groups and telephone interviews were transcribed verbatim, and entered into NVivo11 (Qualitative Software for Research (QSR) International 2017). Applied thematic analysis was used as an exploratory approach to code broad emergent themes (DC). (16) Subthemes that emerged were augmented using both an inductive approach (developed after consultative interpretation of the analysis) and a deductive approach (bound by the intent of informing the development of a health promotion program). Coding was cross-checked by secondary

analysts (IH) and triangulated (DG) to validate interpretations and consistency.

Illustrative quotes are from participants in focus groups (FG) and telephone interviews

(TI) with multiple options proposed by analysts (DC, IH) and chosen with consensus by

all authors.

The prioritisation exercise whereby patients listed their top 5 life priorities at pre- early

post- and post- transplant, was analysed using content analysis to determine the greatest

frequency of stated life priorities clustered across the three pre-determined time points.

(17) Similar meaning words were collapsed into themes and triangulated by an

independent researcher. Frequency of word clusters were matched with identified themes

to estimate when subthemes were most likely to emerge or change over the course of

recovery.

## Results

Figure 1 illustrates the recruitment flow diagram with n=28 agreeing to participate.

Participants were 24 to 68 years old (mean  $53 \pm 13$  years), and 18 (64%) were male.

Median time since most recent transplant was 4 years (range 2 to 5 years). Both focus

groups and telephone interviews consisted of participants from local, regional and

interstate locations. Geographical residence of participants ranged from 13 (46%) being

located within the tertiary hospital catchment area, 6 (21%) within 100km of the hospital

and 9 (33%) >100km from the hospital. Average time for focus groups was 82 minutes

(range 70 – 90minutes) and individual interviews 27 minutes (range 15 - 48 minutes).

Thematic analysis identified three over-arching themes and multiple sub-themes (Figure

2). The timing of when each sub-theme emerged across the transplant journey was

estimated by matching with the frequency of life priorities listed by participants at each of the three pre-defined time points and was determined by consensus amongst investigators (DC, IH, DG, AB)(Figure 2).

## **Finding a Coping Mechanism**

At every stage of transplant (from pre-surgery to many years post-transplant) participants stated that finding a way to cope emotionally and physically with the transplant experience was a high priority and infiltrated most decisions regarding health behaviours.

### ***Facing an unknown future after near-death***

The fear of an unknown future ruminated constantly prior to transplant and left a strong legacy of uncertainty well after transplant that continued to impact on future life plans.

*“The foremost thing was getting a transplant, but not knowing what was ahead of me though, so you don’t really know, it’s one of those things that you think.....is it going to be good or is it going to be bad”(TI,16)*

*“For me every blood test was Russian roulette .....there was always someone who was in some degree of rejection .... so every blood test was you know, is it my turn to find I’m in rejection. That was all the way through that first 12 months.....that weighs very heavy on your mind..... only stuff that sticks in your mind is the bad stuff all of a sudden when you’re lying in bed at 2am” (FG4, 32)*

### ***Emotional and psychological support networks***



Participants expressed the need for emotional and psychological support networks to cope with feelings of guilt and uncertainty at all stages of transplant. Family and social influences could significantly impact adherence to health behaviours in either a positive or negative way depending on the degree of perceived emotional and psychological support received. A common topic that emerged was the importance placed on mentoring or peer support from other LTRs, in the form of social and emotional support.

*“People that had had transplants and they used to come up and give a talk too and they’d talk to you about um you know what they went through and how they handled it and you got to actually talk to them face to face and you could ask them whatever questions you wanted to...That’s the best way if there’s someone [another LTR] close that can organise to meet and just have a talk yeah that’s all they need, a bit of support.” (TI,16)*

However, participants also desired greater psychological support from the hospital clinic to develop coping strategies for stress and anxiety, which they perceived to impact on physical wellness even years after transplant.

*“The psychological aspect as well I’m a big advocate for that I don’t think we do enough in that area as well simply because you know, the transplant friends I have, none of us have ever had any sort of support or anything like that. I think that it’s a big factor that’s sort of overlooked.” (FG,31)*

*“So it was really, also the questions of how to actually maintain a balance in terms of your thinking, you’re sort of in a healing process, yes the physical stuff but also your sort of spiritual healing shall we say.” (FG1, 3)*

202

203 ***Keeping a positive mindset***

204 Participants placed a high importance on optimism and maintaining a positive mindset as  
205 a strategy for coping before and after transplant.

206 *“I’ve got a second chance. I’ve still got these underlying issues; I’ve really got*  
207 *to keep on top of it so you can’t really do that unless you stay*  
208 *positive.”(FG,10)*

209

210 ***Expressing gratitude and giving back***

211 After the early post-transplant recovery, participants had a strong emotional  
212 connection related to a deep gratitude for the ‘gift of life’ and expressed need to ‘give  
213 back’. This was nuanced by personal expression that may have been inward looking  
214 such as motivation to look after the new liver through a healthy diet or outward  
215 looking such as adhering to prescribed hospital advice or offering reciprocal support  
216 for others.

217 *“I’m guessing that most of us go through stages where we feel like you know*  
218 *why us, and you know we’re like eternally grateful for what was sort of given*  
219 *to us so I started to think that what I could do to give something back you*  
220 *know... How could I show that I was just being grateful you know.”(TI,12)*

221

222 ***Taking Responsibility***

223 By later stages of recovery (>6months post-transplant), participants predominantly  
224 wanted to take responsibility for their actions, and take ownership of their own health.  
225 This was a coping strategy that made them feel in control of their health.

226        *“I think maybe just people having, needing, to take the responsibility*  
 227        *themselves and owning what’s going on in their life. You know what I mean*  
 228        *you can have all these people tracking you and following you and advising you*  
 229        *but if you don’t take that responsibility and own it, it doesn’t work.”(FG,20)*

230

## 231    **Back to Life**

232    Participants described a renewed outlook on life and expressed their desire to return to  
 233    ‘normality’ and ‘stability’. The word ‘life’ was used in the context of rebuilding life,  
 234    getting back to ‘normal’ life, ‘making the most of life’ and social life. Seeking a ‘normal  
 235    life’ included recovering physically and emotionally, gaining back independence and  
 236    returning to their ordinary day-to-day activities and way of living.

237

238

## 239        ***Work and Finances***

240

241    Returning to employment post-transplant was of critical importance. It was a prominent  
 242    thought well before transplant and greatly influenced the prioritisation of health  
 243    behaviours that impact on employment or managing finances after transplant.

244        *“It was just trying to get back to work yeah cos you know being sick and being*  
 245        *away from work and being in hospital quite a lot yeah it puts quite a lot of*  
 246        *pressure on the family for bills and stuff like that”(TI,15)*

247

## 248        ***Taking care of and spending time with family***

249    Participants valued family and social connections, and expressed a desire to take care  
 250    of and spend time with their family after transplant.

251        *“Yeah it’s the best thing that ever happened to me you know, one yes I’m still*  
 252        *alive but the lifestyle choices that I’ve made now whereas before we were um*

*driven by material things now we're not. It's more about family and lifestyle  
and you know doing what we actually enjoy rather than you know keeping up  
with the Jones's.*"(FG,31)

### ***Managing medical conditions and coordinating health service***

#### ***interactions***

From an early stage, participants placed a high priority on their long-term wellness and linked that to living a 'normal life'. The management of on-going medical issues, medications and side effects was a significant burden for participants, and outside what most people would consider 'normal'. Participants accepted the need for regular follow-up post-transplant, however expressed a desire for receiving care outside of the hospital/clinic environment. They wanted integration of a wider range of support services such as general practitioners, dietitians and exercise specialists into their post-transplant care schedule.

*"Probably educate the GPs a little bit better... the regime as to what the  
recipient should be doing so that the GP becomes effectively a part of your  
team. On exactly the same wave length of what recipients should be doing as  
you. Even down to little things like the GP should be getting you to get your  
blood tests done, should know the frequency of that."*(TI,8)

*"a long term issue for me to deal with is staying well in regards to having a to  
keep on top of all the other medical stuff that's going on as well."* (FG3,20)

Hospitalisations and outpatient appointments are burdensome, and participants described eagerly anticipating a decrease in frequency of hospital appointments, which was a common metric that they used to gauge their progress.

*“I started off like you monthly and then 3 monthly and then 6 monthly for a couple of years and now its yearly. Yeah its great it’s a good feeling.” (FG,20)*

### **Tailored, Personalised Care**

Participants acknowledged their uniqueness in the community due to their specific requirements relating to long-term health advice and diet and exercise information specific for LTR.

#### ***Practical advice specific for me***

The need for diet and exercise advice to be tailored to the specific needs of liver transplantation and personalised to the individual’s circumstances became evident throughout the data. Participants identified a wide variety of preferences for long-term health care and support but always with a focus on practical advice for approaches to diet and exercise.

*“The information that they give you is just like, it needs to be more tailored to individuals... What information that suits one person probably doesn’t suit everyone. It depends [on] the circumstances you had your transplant under.” (TI,21)*

#### ***Options for accessing support***

Participants' preferences varied for how they thought diet and exercise support post-transplant should be provided. Some had a preference for group-based education; while others wanted one-on-one interactions with health professionals. Participants valued in-person interactions with health professionals and suggested video conferencing for LTR who are not located close to the hospital. There were contrasting views on engaging with technology for diet and exercise support with some LTRs open to innovative technologies, while others objected strongly to this strategy and would prefer telephone follow-up or written resources.

*"I love the electronics but it's not the same as a personal discussion .....  
You've got to use a whole range of things and you know.....a website where  
some generic information goes and then there's more personalised one-on-one  
contact and whether that one-on-one is actually sitting here face to face or  
whether its though skype or something like that because of distance factors."*  
(FG,13)

### ***Timing is right when I'm ready***

Preferences for the timing of receiving post-transplant diet and exercise education ranged considerably. Some participants emphasised the importance of receiving post-transplant diet and exercise information prior to transplantation, while most reported being best placed to receive support within six months of receiving their transplant. There was agreement that if the presentation of a post-transplant wellbeing program is mistimed, unintended consequences could occur, with patients disregarding information or resenting health professionals.

*“You need that [lifestyle related] info pretty much straight away after the transplant to get yourself on the right track. That first 12 months is a real transitional phase for you because you are going through all the healing and stuff. And you don’t really have your head in the place of planning your new life. You have your head in getting through day to day whereas 12 months down the track your mindset has changed by then and you’re starting to focus on what you are going to do with your new life…….”(TI,8)*

Based on a translation of the thematic analysis, key factors informing the development of a post-transplant wellbeing program are identified in Table 1. These include practical recommendations for clinicians to consider when implementing post-liver transplant health services.

## **Discussion**

This qualitative study used a process of knowledge exchange between researchers, clinicians and health system users and highlights the value of using implementation science for the design of new health services. It identified experiences that may influence decisions around health behaviours and informed elements of a post-transplant wellness program for LTR.

While quality of life improves after transplant, participants of this study described ongoing issues associated with mental health and emotional resilience that may impact on health-related decision making.<sup>(18)</sup> Unique emotional stressors such as survivor guilt and post-traumatic stress are recognised in organ transplant recipients.<sup>(19-22)</sup> Study participants indicated that before they could address their diet and exercise needs, they

needed better strategies to cope with the insecurity and uncertainty associated with survival; and also needed the physical and emotional resources to deal with their current medical issues. Regular exercise and improving diet quality are effective strategies for fostering good mental health and cognitive function after significant health events such as cardiac arrest. <sup>(23-25)</sup> However, participants in this study did not identify such health behaviours as coping mechanisms *per se*. This finding has significant implications for transplant services that may not typically offer psychological support or peer mentoring programs as standard care. The desire for professional emotional support emphasises the need for multi-disciplinary teams before and after transplant. The provision of group psychotherapy to patients awaiting liver transplant has uncovered some reluctance to engage with these strategies but warrants further investigation due to the potential benefits such as reduced anxiety and sharing experiences with others<sup>(26)</sup>.

Based on the responses from this cohort of LTRs it seems important at the outset of a health promotion program to formally recognise the emotional burden of receiving a transplant and the influence of post-traumatic growth on well-being and health behaviours post-transplant<sup>(27)</sup>. Incorporating LTR peers into the delivery of the program will offer another vehicle for emotional support and also serve as a mechanism to develop partnerships with knowledge users who acknowledge a responsibility to live a healthy life. <sup>(19, 28)</sup>

Participants placed a high priority on getting back to 'normal life' despite reconciling their reality that interacting with health services and self-monitoring will be a life-long burden that others do not bear. The importance of regaining independence, such as being able to drive and travel, and returning to work, are common themes post-organ transplant.



(29) The experience of this cohort was that re-entering the workforce was a high priority, contributed to financial recovery, social functioning and establishing a work-life balance that reflects emerging wellness. These results can inform the structure of program delivery whereby the need for recipients to prioritise and balance work commitments with recommended health behaviours are acknowledged and accommodated.

Participants in this study desired tailored, personalised health care, with practical guidance to help them self-manage diet and exercise. Rather than a lack of understanding around the benefits of exercise, participants expressed uncertainty around how best to commence strenuous physical activities due to feeling ill-equipped to judge the safety of exercise. Fear associated with physical capabilities post-transplant has been recognised in other organ transplant groups. (28) Guided, tailored prescription of exercise pre- and early post-transplant may overcome this barrier.

A tension exists between participants' preference to maintain relationships and monitoring by specialist health professionals with the desire for a life free from hospital appointments. While the LTRs wanted expert advice for key aspects of care such as emotional needs and exercise prescription, there was a commitment to take responsibility for the long-term self-management of their wellbeing. This paradox may be addressed with flexible telehealth access to specialist care within the context of predominantly home based, self-directed support programs.

Considering the stated financial concerns of LTR, and the geographical dispersion of a state-wide transplant service; utilising telehealth platforms and technology to offer

hospital-to-home group support for long term health behaviour change may improve effectiveness and equitable access. <sup>(30-33)</sup>

This study highlighted the need for some degree of patient-led process for how and when post-transplant health services are engaged by LTR. Recipients desire an awareness of available resources at early stages of the transplant experience, however the readiness to engage differs for each LTR. In addition, it was identified that life priorities change over the course of recovery, which may impact on readiness to engage with wellness programs. There is likely to be greater uptake and effectiveness if the health system can support an inherently flexible user-led approach to uptake of service delivery and potentially screening LTR and their carers for readiness to engage may be worthwhile to improve uptake.

The results of this study contribute to person-centred health care design by creating partnerships between researchers and the people for whom the research is ultimately meant to be of use. <sup>(34)</sup> This challenges assumptions of experts and values the consideration of LTR life priorities during the course of recovery.

The study has used robust qualitative methods to involve knowledge users in research. Many aspects of this study decreased barriers to inclusion such as giving participants options for data collection methods (phone interviews or focus groups) including regional and metropolitan residents, and increased face validity by secondary analysts performing data triangulation. Question development involved a multidisciplinary team, which increased internal consistency. Due to the voluntary nature of the study, it is possible that the participants were over-represented by those who have had a positive transplant and/or

healthcare experience. In addition, all participants were asked to recall their pre-transplant experiences and perceptions which may have been more than 12 months prior for some participants and introduces recall bias for pre- and early-post transplant time points. The results are contextual to an Australian, English-speaking transplant population and may not be generalizable to other countries and cultures.

## **Conclusion**

This interactive qualitative process of knowledge exchange focused on the experiences of LTRs and identified life priorities most likely to influence decision-making related to health behaviours post-transplant. Users co-creation of services has the potential to improve the integration of knowledge into health systems and improve patient outcomes. The future direction of this patient engagement process will involve the implementation and evaluation of technology-assisted lifestyle intervention for liver transplant recipients.

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**Table 1: Key insights from LTRs to inform the design of a post-transplant diet and exercise program**

Key Insights
<ul style="list-style-type: none"><li>Consider the psychological and emotional health of the patient at entry to the program, and the influence of mental health status on decision-making related to health behaviors</li></ul>

- Include mentoring and networking with other LTR to share experiences and facilitate group interactions with people at different stages of recovery
- Potential recipients should be made aware of available post-transplant diet and exercise resources prior to transplant, but be able to choose when and how to engage with these resources
- Service delivery options that include tele-health and video connections for face to face contact should be included, with flexible access times to suit employment and family commitments
- Program to be delivered by health professionals with expertise in liver transplant
- Program information to be pitched with positivity regarding maintaining health and wellbeing rather than reminding patients of links with illness and chronic disease

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570 **Figure Headings**

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572 **Figure 1:** Study participant recruitment flow diagram

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575 **Figure 2:** Three overarching themes with subthemes emerging across the liver

576 transplant journey, which have potential to impact the design of diet and exercise

577 wellness programs.

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